
OLR Bill Analysis

SB 465

AN ACT REQUIRING NEWBORN SCREENING FOR ADRENOLEUKODYSTROPHY.

SUMMARY:

This bill adds adrenoleukodystrophy to the list of genetic and metabolic diseases for which hospitals and other institutions must test newborns under the Department of Public Health's (DPH) newborn screening program. The law requires such testing to be performed as soon as medically appropriate, unless a parent objects on religious grounds. In addition to the initial screening test, the program directs parents of identified infants to appropriate counseling and treatment.

EFFECTIVE DATE: October 1, 2013

BACKGROUND

Adrenoleukodystrophy (ALD)

ALD is a genetic disorder that causes the accumulation of very-long-chain fatty acids in the nervous system, adrenal gland, and testes, which causes a range of neurological, physical, and behavioral symptoms. While females are genetic carriers for the disease, it primarily affects males.

Generally, the disorder appears between ages four and eight, although milder forms can occur in adulthood. Childhood onset results in a long-term coma approximately two years after the development of neurological symptoms. The child can live in this coma for as long as 10 years until he or she dies.

There is no specific treatment for ALD, but eating a diet low in very-long-chain fatty acids and taking special oils (called Lorenzo's oil) can lower blood levels of these fatty acids.

Newborn Screening Program

DPH's newborn screening program requires all health care institutions caring for newborn infants to test them for:

1. phenylketonuria and other metabolic diseases,
2. HIV,
3. hypothyroidism,
4. galactosemia,
5. sickle cell disease,
6. maple syrup urine disease,
7. homocystinuria,
8. biotinidase deficiency,
9. congenital adrenal hyperplasia, and
10. other tests for inborn metabolic errors DPH prescribes.

Separate from the newborn screening program, the law also requires these institutions to test infants for critical congenital heart disease, cystic fibrosis, and severe combined immunodeficiency disease.

Related Law

The law requires individual and group health insurance policies to cover certain food products (e.g., acid modified preparations and low protein modified food products) used to treat inherited metabolic diseases (CGS §§ 38a-518c and 38a-429c).

COMMITTEE ACTION

Public Health Committee

Joint Favorable

Yea 28 Nay 0 (03/11/2013)